



Help-seeking intentions for early dementia diagnosis in a sample of Irish adults

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Abstract

Objectives: To identify factors that may increase intentions to seek help for an early dementia diagnosis. Early dementia diagnosis in Ireland is low, reducing the opportunity for intervention, which can delay progression, reduce psychological distress and increase social supports.

Method: Using the Theory of Planned Behaviour (TPB), and a mixed methods approach, 3 focus groups were conducted (N=22) to illicit attitudes and beliefs about help seeking for an early dementia diagnosis. The findings informed the development of The Help Seeking Intentions for Early Dementia Diagnosis (HSIEDD) questionnaire which was piloted and then administered to a sample of community dwelling adults from Dublin and Kildare (N = 95).

Results: Content analysis revealed participants held knowledge of the symptoms of dementia but not about available interventions. Facilitators of help seeking were family, friends and peers alongside well informed health professionals. Barriers to seeking help were a lack of knowledge, fear, loss, stigma and inaccessible services. The quantitative findings suggest the TPB constructs account for almost 28% of the variance in intentions to seek help for an early diagnosis of dementia, after controlling for sociodemographic variables and knowledge of dementia. In the final step of the regression analysis, the main predictors of help seeking were knowledge of dementia and subjective norm, accounting for 6% and 8% of the variance respectively.

Conclusion: Future interventions should aim to increase awareness of the support available to those experiencing early memory problems, and should highlight the supportive role that family, friends, peers and health professionals could provide.

Key words: Dementia, help-seeking intentions, attitudes, subjective norms and perceived behavioural control

Introduction

Dementia is a major health care concern worldwide, impacting upon cognitive functioning, memory, language, personality, mood and quality of life of the person. It is estimated that 35.6 million people in the world have dementia, which is set to double every 20 years, to an estimated 115.4 million in 2050 (Alzheimer's Disease International, 2013). Figures in Ireland for 2011 were estimated at 41,740 (Cahill, O'Shea & Pierce, 2012) and will increase to around 152,157 by 2046 (The Irish National Dementia Strategy, 2014). An early diagnosis for dementia is being encouraged within national strategies for improving dementia care, in some European countries; such as Ireland (The Irish National Dementia Strategy, 2014), Northern Ireland (Improving Dementia Services in Northern Ireland- A Regional Strategy, 2011) and the UK (National Dementia Strategy for the UK, 2009), but is not recommended by the UK National Screening Committee or the US Preventative Strategies Task Force (Le Couteur et al. 2013). The aim is to provide better support services for patients and their carers', and for the patient to make informed choices about health care and financial arrangements while they are able to do so.

There is controversy around as an early dementia diagnosis as it may not meet the WHO's criteria for health screening (Wilson & Jungner, 1968), as it is unclear how it will prevent the onset, or delay progression, of the disease as there is no cure nor effective interventions. However, an early diagnosis is considered to be essential to successful future health care planning given increased longevity (World Alzheimer Report 2011; World Health Organisation, 2014; Robinson, Tang & Taylor, 2015). It is based on an assumption that early intervention may be more cost effective with limited evidence to support this (Corbyn, 2013; Marshall et al., 2015) and also to gain

greater insight into how interventions may delay disease progression (Panegyres et al., 2016). The early or pre dementia pathways are not well understood as not everyone will develop dementia that presents with memory problems (Mitchell & Shiri-Feshki, 2009). Caution is also warranted for the blanket application of Advanced Care Planning (ACP) upon diagnosis, as its success is dependent upon appropriate timing and patient engagement (Robinson, Dickinson, Rousseau et al., 2012).

The World Alzheimer's Report (2011) identifies diagnosis as a human right and strongly recommends disclosure, even though dementia was reported to be the most feared diagnosis in adults over 55 years (Brunet et al., 2012). Arguments against disclosure can be linked with health practitioner negative attitudes and attempts to protect the dementia patient from diagnosis related distress (Bradford et al., 2010; Milne, 2010; Moore & Cahill 2012). This may lead to a decline in status, job loss, changes in relationships with family and friends, the acquisition of a stigmatising label and an increase in feelings of anger and frustration (Bunn et al., 2012), risk of depression and anxiety (Milne, 2010) and suicidal tendencies (Draper et al., 2012), with diagnosis. All of these may impact on help-seeking behaviours (Phillipson, Magee, Jones & Skladzien 2012; Clement, Schauman, Graham et al., 2014). Better support services are needed post diagnosis for carers and patients (De Vugt & Verhey, 2013), however, this may mean diverting health resources away from other areas (Brayne & Davis, 2012; Le Couteur et al., 2013).

On a more positive note, early diagnosis may enhance understanding of the impact of modifiable lifestyle factors on the disease process and the impact of interventions such as counselling (Panegyres et al., 2016). It allows optimal medical

management to delay progression (Panegyres et al., 2016), rule out other aetiologies' (Bradford et al., 2010), support risk reduction (Martin, Marottoli & O'Neill, 2013) and is associated with reductions in care giver burden, fear and anxiety (World Alzheimer's Report, 2011). Confirmed diagnosis can bring relief to carers in some cases and paves the way for acceptance and adaptation to the diagnosis (Du Vugt & Verhey, 2013) and planning for the future. It also allows opportunities to work with carers in a skills training capacity to promote appropriate coping mechanisms.

The Theory of Planned Behaviour (TPB) (Ajzen, 1988) offers a framework to address the attitudes and beliefs which influence help-seeking for an early dementia diagnosis. The TPB suggests that attitudes (formed by knowledge and prior experience) are a strong indicator of intentions, as are subjective norms (SN) (how much social pressure does the person feel to carry out the behaviour) and perceived behavioural control (PBC) (how much control does the person feel they have over the behaviour). Connor & Sparks' (2005) review of the TPB found attitude was the strongest predictor of behavioural intentions for health screening. While both SN and PBC have a medium sized relationship with intention, PBC has only a small relationship with actual screening uptake (Cooke & French, 2008). Decisions regarding intentions to seek help were considered likely to be weighted by knowledge and attitudes held towards dementia, help-seeking behaviour, control beliefs and outcome evaluations regarding the personal consequences of early diagnosis and intervention (Galvin et al., 2008; Frost, Myers & Newman, 2001, Phillipson et al., 2012). Where increased knowledge of dementia and its symptoms and perceived benefits of post diagnosis interventions were found to be predictive of screening and help seeking intentions (Galvin, Fu & Schariff, 2008; Helmes, McKirdy &

Caltabiano, 2010). Werner, Mittleman, Goldstein and Heinik (2012) found knowledge correlated with reductions in self-stigma and public stigma. In contrast, Boustani, Justiss, Frame et al. (2011) found caregivers as less likely to agree to dementia screening and having higher perceptions of suffering.

While there is a strong body of TPB research investigating health screening attendance, only one addresses a similar topic. Frost et al. (2001), using the TPB and measures of risk perception, anticipated regret, Alzheimer's Disease (AD) risk factors and the likelihood of taking a genetic test for familial Alzheimer's disease, reported just over 50% of the variance in intentions related to the above in addition to the number of people known to have AD . SN was found to be the most significant predictor of intention to screen for genetic AD in the increased certainty group.

Given the established utility of the TPB, the international trend towards encouraging early dementia diagnosis and the low uptake of the same within Ireland (Cahill et al., 2012), this study has utilised the TPB to consider the variables which influence help-seeking behaviour for early dementia diagnosis. To our knowledge this is the first study to address this help seeking behaviour, using a theoretical framework and therefore filling a gap in the literature. Culturally specific empirical evidence may support health policy and practice to develop future interventions and to increase help-seeking behaviours associated with memory problems in younger adults (50+). This study will look at how the TBP variables (attitudes, SN and PBC) predict intentions to engage in health seeking behaviour for an early diagnosis of dementia in Irish adults aged 50-69 years.

Method

Design

The current study is a mixed methods (focus groups and quantitative questionnaire study) sequential exploratory design (Creswell, 2003) using the TPB. A structured interview schedule was developed to uncover the salient behavioural, normative and control beliefs participants held about help-seeking intentions regarding early dementia diagnosis (Francis, Eccles, Johnston et al., 2004). Three focus groups (FGA, N = 7), (FGB, N = 7), (FGC, N = 8) were conducted. Data elicited from the focus groups was analysed using an inductive content analysis and the results were used to inform the design of a questionnaire to assess these factors in a larger sample. The newly developed questionnaire was assessed via a pilot study (N = 5) in which no difficulties or requirements to alter the questionnaire emerged. The questionnaire measured demographic variables, knowledge of dementia symptoms alongside TPB constructs; generalised intentions, attitudes, SN and PBC of participants in relation to their help seeking intentions' for early dementia diagnosis.

Participants

Participants were a opportunistic sample of community dwelling adults, aged 50-69 years and living in Kildare and Dublin, Ireland, recruited from community groups catering to this age range and acquaintances' of the researcher (SD) who met the inclusion criteria. This age limit should reflect older adults with normal cognitive function, in the absence of neurodegenerative disease. The upper age limit was established due to ethical considerations and previous research that suggests a decline in cognition occurs beyond 70 years (Simpson et al., 2005), and the lower age limit, to address a life stage population, those who may worry about the onset of memory

problems. Participants within the three focus groups were as follows: (FGA (N = 7, all female, aged 50-67 years) Aylmer Park Group, Kildare; FGB (N = 7, all female, 50-69 years), The Women's Group, Red Rua, Dublin; FGC (N = 8, 6 female, 2 male, aged 50-69 years), Aylesbury, Dublin) were known to each other, three people declined to take part due to time constraints, not interested in the study, and lastly no reason given. For the quantitative stage, 39.8% of those approached declined to take part. All participants undertook a Mini Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975), all participants scored within a normal range.

Pilot questionnaire participants (N = 5) meeting inclusion criteria were recruited via acquaintances' of the author (SD). As no changes were made to the questionnaire post piloting, the data from the pilot stage was included in analysis. The questionnaire was applied to focus group members (N = 22) and further extended to other members of the above mentioned groups as well as other relevant community groups (Kilnamanagh Community Centre, Dublin, (N = 3); The Postal Club, Kiltipper, Dublin (N = 23); Aylmer Park Group, Kildare (N = 11); The Women's Group, Red Rua, Dublin (N = 8) and acquaintances' (N = 23) meeting inclusion criteria. It is considered that a sample size of 80 is acceptable for producing a moderate effect size for TPB studies that use a multiple regression analysis (Francis et al., 2004), the current study has exceeded this (N = 95).

Materials

Documentation included two participant information sheets and consent forms specific to the qualitative and quantitative stages of this research. All participants were screened for possible cognitive decline, using the Mini Mental State

Examination (MMSE) (Folstein et al., 1975); a brief 30 item questionnaire measuring orientation to time and place, immediate recall, short term verbal memory, calculation, language and construct ability, found to be reliable at ruling out cognitive decline in community settings (Mitchell, 2008), with a standard cut-off score of 24 or under. Participants, who scored below the cut-off, were to be referred to their GP for further follow up.

A customised structured interview schedule developed by Francis et al. (2004) was employed during the focus groups. Attitudes and behaviour were assessed by asking questions on the meaning of dementia, 3 questions addressed behavioural intentions and attitudes towards early dementia diagnosis, 3 questions addressed SN and the final 3 questions focused on perceived behavioural control. The focus groups were audio recorded using a Toshiba Laptop with a Window 8 Media Audio File Application. A debriefing guideline schedule for the focus groups, the newly developed HSIEDD questionnaire and a debriefing sheet for use following the questionnaire were also used.

Questionnaire development: Help Seeking Intentions for Early Dementia Diagnosis (HSIEDD). Knowledge and salient belief statements were developed from the most frequently occurring participant responses, which in turn were used to construct questionnaire items (see Table 1 for example of direct measurement questions). Six questions elicit demographic information, 3 assess knowledge of dementia, while the remainder questions were based on the TPB framework; 3 measured generalised intention, 4 assessed direct measures of attitudes, 16 assessed indirect measures of attitudes (8 behavioural beliefs evaluated on a unlikely/likely

dimension, 1-7; 8 outcome evaluations responding to an extremely undesirable/extremely desirable scale, -3/+3); 4 assessed direct measures of SN, 12 measured indirect SN (6 normative beliefs measured on an approval/disapproval scale 1-7; 6 motivation to comply measured on a not at all/very much scale 1-7); 4 assessed direct measures of perceived behavioural control, 20 questions assessed indirect measures of perceived behavioural control (10 control beliefs measured on a unlikely/likely scale -3/+3; 10 power of these factors to influence behaviour measured on a less likely/likely scale -3/+3). The above questions were randomised as is observed to be best practice (Francis et al., 2004).

Procedure

Ethical Approval was obtained from the School of Psychology Staff and Postgraduate Filter Committee, Ulster University. Focus Group: an information sheet about the nature of the study, the right to withdraw, intentions to record, confidentiality and data storage was given to all participants prior to written consent being obtained. All participants scored above 24 on the MMSE, undertaken privately with the researcher. For the focus groups, seating was arranged in a semi circle, with participant identifiers incorporating relevant group name (A, B or C) and numbers 1-7/8. Focus groups were guided by the researcher, using the structured interview schedule and directly followed by debriefing informing the participants of resources available to them.

Questionnaire study: the findings from the focus group study were used to develop a questionnaire (HSIEDD) to assess intentions, attitudes, subjective norm and perceived behavioural control. The questionnaire was piloted and administered in the following way. Participants were provided with a participant number, an information

sheet, informing them of the nature of the study, the right to withdraw, confidentiality and data storage, followed by a consent form to be completed prior to taking part. Firstly, all participants completed the MMSE (Folstein et al., 1975) privately with the researcher; those with normal scores completed the self-report HSIEDD, with the researcher providing support if requested. On completion questionnaires were handed back to the researcher for data analyses.

Data Analyses

Focus groups: duration of the focus group recordings varied (FGA: 22:50 minutes, FGB: 21:37 minutes, FGC: 27:51 minutes). Data from the three focus groups was transcribed verbatim by one of the authors (SD). As recommended by Francis et al. (2004), the two researchers (LS & SD), working independently, conducted content analyses using an inductive approach to identify themes (Elo & Kyngas, 2008). Concepts were derived from the data; sub themes were generated (95.5% agreement), labelled and reviewed again before overarching major themes (100% agreement) were established. Discussion between the researchers resolved any differences within the categorisation and labelling process. The researchers, throughout the analyses and the write-up, have reflected upon their influence on the results.

Questionnaire study: all TPB items were scored as recommended by Francis et al., (2004). The overall score of the direct measurements were calculated by recoding items with negatively worded end points, before calculating the mean, weighting each behavioural belief by the score of the relevant outcome evaluation. Secondly, by weighting each normative belief by the score of the relevant motivation, to comply with the behaviour. Thirdly by weighting each control belief by the score of the

relevant power to influence behaviour. Finally, a sum of all weighted beliefs for each construct was calculated (attitude, SN and PBC).

Data was coded, inputted and analysed using SPSS (version 20.00) by employing frequencies, independent T-tests, ANOVA, correlation coefficients and a hierarchical linear regression analysis. Preliminary analyses, descriptive statistics and checks for missing data, normal distribution and outliers of the data were conducted, prior to statistical analyses. There are rules of thumb for skewness and kurtosis which indicate that skewness of a range of +2 to -2 does not require data transformation (Kline, 2010; Tabachnick & Fidell, 2007) and for kurtosis anything over 10 should be transformed (Kline, 2010). A series of normal distribution plots were created and inspected. All were within an acceptable range (Field, 2009).

Results

Focus group findings

The major themes are given as sub-headings and sub-themes are described within each section, quotes can be found in Table 2.

Knowledge of dementia

Memory loss, confusion, behaviour change and changes in a persons understanding of their world were all noted as symptoms of dementia. Dementia was recognised as an age related disease, where some participants held an expectation that memory loss in old age was inevitable (see Table 2 (a)).

Attitudinal beliefs

Treatment to delay progression; considered to be an option by some, but many participants were unaware of available interventions. *Planning for the future*; many participants felt that planning for the future extended autonomy and increased control over future care options. *Increased social supports*; participants were divided in the belief that increased social supports would be available, while family were often recognised as increasingly supportive, state funded social supports were deemed by some to be unavailable. *Impact of diagnosis*; participants observed the difficulties of dealing with an early diagnosis and found it to be the most notable disadvantage of seeking help early. Negative emotions such as fear, shame, and denial, loss of hope, status and autonomy were identified. Learning to cope with the changes in behaviour, relationships, lifestyle and the possibility of institutional care were also concerns.

Lack of options some participants felt there were no advantages of seeking help, as there was no cure, no medication, and no opportunity to plan (see Table 2 (b)).

Normative beliefs

Health professionals, family, friends and peers were considered most likely to approve of a participant seeking an early dementia diagnosis. *Employers, older adults, young adults and teens* were considered to be the most likely to disapprove. Employers were regarded as disapproving given potential implications for workers role, older adults were viewed as disapproving given perceptions of shame, fear and previous experiences. Younger adults and teens were seen as disapproving as a result of immaturity and lack of knowledge (see Table 2 (c)).

Control beliefs

Family, friends and peers were unanimously seen as the most important factors in supporting someone in seeking diagnosis. *Health care professionals*, GP's, nurses, specialist clinics, health centres and support groups were also seen by many as facilitators of help seeking. *Fear, stigma and shame, a lack of knowledge, and coping style* were seen as barriers to help seeking. *Accessibility of services*; such as difficulties within the GP/ patient relationship, financial costs and demographic location were also observed as barriers to help seeking (see Table 2 (d)).

Questionnaire study

The profile of the sample

The participants in the quantitative stage of this research were mostly urban dwelling females (F = 68; M = 27) with post primary education. MMSE scores were high with 53% scoring full marks and 17% and 11% scoring 29 and 28 respectively. Of the lower scores 7% scored 27 and only 3% scored 25 on the 30 point scale (see Table 3).

Reliability of the HSIEDD

In order to assess the reliability of the newly developed measure, a Cronbach's alpha was established for all subscales of the HSIEDD (see Table 4). A Cronbach's alpha at or above .6 is considered acceptable by Francis et al. (2004) but a figure at or above .5 has been accepted in previous studies (Bowling, 2002). Where the Cronbach's alpha was below this figure, items were removed to increase reliability (K1, RA2*, RA4*, IA5, IA7, IA8, RSN1*, RSN4*, PBC1, PBC2, * reverse coded items). The Corrected Item-Total Correlations were considered if an acceptable alpha could not be achieved. Item correlations above .3 can be considered to be well correlated within a

questionnaire (Field, 2009). In this light, analysis indicates that MGI, MPBC, OIDMA, OIMSN and OIMPBC have good reliability. MK ($\alpha = .480$) is approaching reliability and all corrected total item correlations are above .3, indicating good correlation within the questionnaire, so were included in further analyses. Two direct measurement subscales (DMA and DMSN) have low reliability and corrected item-total correlation below .3 and were therefore removed from further analyses.

Group differences on the TPB subscales for sex, age and education

A series of independent T-Tests were conducted on the reliable subscales (MK, MGI, MPBC, OIMA, OIMSN and OIMPBC), and indicated no sex differences ($P > 0.05$). Further analyses, using ANOVA was undertaken on the reliable subscales and indicated no differences for age (50-54; 55-59; 60-64; 65-69) and education (primary cert; secondary cert; third level; other) for any of the subscales ($P > 0.05$).

Relationships between the TPB constructs

Prior to regression analysis, the relationship between the attitudes, SN, PBC and generalised intentions constructs were analysed using Pearson's bivariate correlations (see Table 5). As expected there are some relationships between the variables. It is evident that the correlations are consistently small to moderate and therefore acceptable for regression analysis (Ajzen 1985).

Predictors of help seeking behaviour

A hierarchical linear regression analysis was conducted to determine what predicts intentions to seek help for an early diagnosis if participants were to experience symptoms of dementia. The TPB predicts that help seeking intentions are influenced by attitudes (formed by knowledge), SN and PBC. It is predicted that knowledge of,

and attitudes towards dementia, its symptoms and available interventions will influence help seeking intentions. It is also predicted that those who believe family, friends, peers and health professionals support help seeking will be more likely to intend to seek help. As shown in Table 6, the socio-demographic variables (age, sex and educational levels) were not predictive of intentions in step one of the model ($p = .402$). There was no change in the R^2 with the addition of knowledge in step two of the model ($p = .12$), but a change was found with the addition of the TPB constructs in step three ($p = .002$), accounting for almost 28% of the variance in intentions after controlling for socio-demographic variables and knowledge. In the final step of the regression analysis, the only predictors were indirect measures of subjective norm ($\beta = .011$, $p = .009$), and knowledge ($\beta = .339$, $p = .023$). In terms of their unique contribution to variability on generalised intentions, as expected, individuals were more likely to seek help for an early diagnosis if they were more strongly influenced by family, friends, health professionals and peers (OIMSN; $\text{spc}^2 = .0784$, knowledge; $\text{spc}^2 = .06$) and if they had more knowledge about the symptoms of dementia and available interventions, accounting for 8% and 6% of the variance, respectively.

Discussion

To our knowledge this is the first study to investigate the contribution of TPB variables of attitudes, normative beliefs and control beliefs in an Irish sample, towards help seeking intentions for an early dementia diagnosis. These variables accounted for 28% variability in intentions after accounting for socio-demographic variables and knowledge of dementia. The main predictors of health seeking intentions for an early dementia diagnosis, in the final step of the regression analysis, were indirect measures of SN and knowledge of dementia, accounting for 8% and 6% respectively of the

variance in intentions. This is similar to the findings of Frost et al. (2001), using an extended version of the TPB, reported SN was the most significant predictor of intentions to screen for familial AD, accounting for 30% of the variance. Galvin et al. (2008) in an extended Health Beliefs Model (HBM) found knowledge to be a predictor of intentions to screen for AD and was positively correlated with perceived health benefits of screening and susceptibility to the disease.

The amount of variance accounted for by a TBP model seems to depend on the health behaviour under investigation, for example, 73% variance in intentions to donate blood (Giles, McClenahan, Cairns & Mallett, 2004); 79% of the variance in males intentions to support breastfeeding, and 58% of the variance in females intentions to breast feed (Giles, Connor, McClenahan et al., 2007). The current study variance may be explained by a recent systematic review, suggesting that dementia screening is not widely accepted by older adults due to the stigma associated with a diagnosis and the poor prognosis (Martin, Kelly, Khan et al., 2015). Influencing how participants regard dementia and when it becomes relevant to them. The majority of the current sample were under 65 years, cognitive decline is usually not evident until after 70 years in normal cognitive ageing (Simpson et al., 2005), with the greatest incidence of dementia occurring in those over 80 years (McGill, 2010). In the current study, the low variance accounted for may be a lack of consideration and relevance given to their risk of dementia and help seeking behaviour associated with it.

Findings from the elicitation study show participants were aware of the signs and symptoms of dementia, but suggested memory decline was an inevitable aspect of ageing and were unaware of available interventions, such as memory clinics. This

lack of knowledge is also evident in the literature; Hamilton-West et al. (2010) have noted that this could lead to a delayed intervention or diagnosis being overlooked. Planning for the future was considered by most participants to be a positive aspect of early diagnosis, reflecting the international perspective for encouraging early intervention (World Alzheimer's Report, 2014).

Accessing increased social support was divisive as many participants felt that family and friends would increase the level of support provided, but increasing state funded social supports was considered difficult or inaccessible by some participants. This response reflects the current status of dementia care within Ireland, where family members provide the majority of care (Cahill et al., 2012). Also, there is a lack of awareness of potential psychological support following diagnosis, even though it is well acknowledged in the literature that depression and emotional distress post diagnosis can occur. Future educational interventions should highlight that negative emotional responses for most people are temporary (Vernooij-Dassen et al., 2006; Robinson et al., 2011) and that psychological assistance can improve outcomes (Orgeta et al., 2014), if it is provided.

Fear, stigma and shame emerged as barriers to help seeking. Negative perceptions of mental illness and dementia are well documented within the literature (Phillipson et al., 2012). A lack of knowledge about where to seek help, highlighting the need for further education (Werner et al., 2012; Hamilton-West et al., 2010) and difficulty accessing appropriate services emerged. Findings are not unexpected. Bradford et al. (2010) noted some of the main contributory factors to be resource constraints and problems within the patient/ provider (GP) relationship, these

concerns have also been observed by Milne, Woolford, Mason & Hatzidimitriadou (2010) who noted the attitudes of GP's were often weighted with negative perceptions of dementia and dementia disclosure.

Family, friends and peers were considered to be the most likely to support help seeking behaviours, followed closely by health professionals. These results support the literature, with current educational interventions aimed at the general public and the health professional (Bradford et al., 2010; Cahill et al., 2012; WHO, 2014). Future educational interventions may focus on this aspect, alongside the advantages, and limitations of medical, psychological and social interventions.

The TPB model, although one of the most widely used theories in behaviour change research, to enhance understanding of predictors of behaviours and intervention design, it is not without its criticisms. Indeed, Ajzen (2011) acknowledges that the constructs do not account for all of the variance in behaviour, concerns over clarity of item design, meaning, length and construct validity have also been noted (Darker & French, 2009; Giles et al., 2007; Fernandez-Ballesteros 2003). The direct measures for attitudes and SN were excluded, in the current study, on the basis of low internal reliability (Bowling, 2002; Field, 2009; Francis et al., 2004). Francis et al. (2004) note the importance of a high internal consistency and observe the potential for the direct measure constructs to result in low internal reliability, possibly reflecting '*indiscriminate use*' of sample items provided in the manual. It is considered that the stem question for the direct measure of attitudes and SN within this study reflects accurately the behaviour under investigation. Darker & French (2009) found participants were interpreting the questions differently than had been

originally intended. Francis et al. (2004) observe the potential need to rephrase questions post pilot study. In this study no difficulties emerged during the piloting stage (N = 5). However the pilot sample may have been too small to uncover difficulties, Giles et al., (2007) piloted their TPB questionnaire amongst a much larger population (N = 121). There may also be an element of ‘unrealistic optimism’ (Weinstein, 1980), where participants may feel that intentions to help seek for dementia diagnosis will not apply to them, as attitude is influenced by perceived risk and personal relevance (Martin et al., 2015; Morrison & Bennett, 2012). Fernandez Ballesteros (2003) also notes the potential to increase reliability on the direct constructs by increasing the number of items. Further investigation as to the direct measures of attitudes and SN within this population is warranted.

Difficulties with the TPB model have been noted previously, two of these concerns emerged within the data collection process. Participants felt the questionnaire was unduly long and repetitive; indeed this is a common argument (Giles et al., 2007). A test-retest reliability analysis (Francis et al., 2004) on the indirect measures is preferred. However, difficulty in accessing the community groups post data collection made further requests for repeat data collection prohibitive. However, despite these limitations, this research addresses a gap in the literature, as currently no study has looked at help-seeking intentions for early dementia diagnosis within an Irish population. The main findings in both stages of the research are supported within the literature but additional work is needed to determine the generalizability of the findings.

Conclusion

Findings indicate that knowledge of dementia and indirect measures of subjective norms are the main predictors of intentions to seek- help for an early dementia diagnosis. The model accounted for 28% of the variance for intentions, after controlling of knowledge and sociodemographic variables. Participants held a good knowledge of dementia but poor knowledge of the available post diagnosis interventions. Family, friends, peers, and health professionals would be most supportive of help seeking, while stigma, fear and lack of knowledge were identified as the main barriers to help seeking. It is suggested that future interventions or campaigns are aimed towards the general public and focus upon increasing knowledge of dementia and the benefits of early diagnosis, with emphasis placed upon services and interventions available post diagnosis. Emphasis should also be placed upon the role of family, friends, peers and health professionals in supporting early diagnosis. More research is needed to confirm these findings.

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Table 1: Direct measures of the Theory of Planned Behaviour

TPB* construct	n items	Sample item
Intention	3	If I experience symptoms of memory loss, confusion, or behaviour changes I intend/expect/want to seek help for an early dementia diagnosis.
Direct measure of attitude	4	Overall I think that seeking help for a dementia diagnosis is: harmful/beneficial, worthless/useful.
Direct measure of subjective norm	4	Most people who are important to me would want me to seek help for an early diagnosis. Likely/unlikely
Direct measure of Perceived behavioural control	4	I am confident that I could seek help for an early dementia diagnosis if I wanted to. Strongly disagree/ strongly agree

*TPB=Theory of Planned Behaviour

Table 2 Themes and sub-themes from the focus groups

Major themes	Sub themes	Participant quotes
2a Knowledge of dementia		
Age related degenerative disease	<ul style="list-style-type: none"> Older adults are more likely to get it Older adults are more likely to ask for help Associated with an expectation around memory loss and may contribute to dementia being overlooked Younger adults can also develop it and are more likely to seek help 	#FGA6 'I associate it with old age; you know em, #FGA3 'Yeah, the same, I'd say we all say the same #FGC7 'I mean I would call it as a disease cos it is
Changes in the person	<ul style="list-style-type: none"> confusion memory loss behaviour understanding of their world 	#FGA1 'Memory loss, memory loss...confused and #FGB2 'You go back to being childlike...'
2 b Attitudinal beliefs of the advantages of help-seeking for an early dementia diagnosis		
Treatment to delay Progression	<ul style="list-style-type: none"> medication maintain normal life for longer 	#FGA1 'Like is there medication?' #FGA4 'Well, I would have thought that with an ea
Planning for the future	<ul style="list-style-type: none"> extended autonomy- input/control over future care and planning options reduce fear and anxiety acceptance of diagnosis 	#FGA5 'that is seen as one of the benefits alright is with your family ...if I have dementia...what we wi
Increased social supports	<ul style="list-style-type: none"> from family, friends, peers and community from health professionals 	#FGB4 '...but certainly family would be supportive #FGC3 'Well the community nurses and things like #FGB3 'your local GP, and your health centre, and
2 b Attitudinal beliefs of the disadvantages of help seeking for an early dementia diagnosis		
Impact of diagnosis	<ul style="list-style-type: none"> Dealing with negative emotions; Fear, shame, denial. Coping with change; Behaviour, relationships, lifestyle, institutional care Coping with loss; Loss of self, loss of status (stigma), loss of control/autonomy, loss of hope 	#FGA2 'and you will lose everything...I think I wo #FGA4 'I'd say there would be a lot of secrecy inv #FGA1 'When you heard the word dementia you lo #FGA4 'people might say' do you know I think it v #FGA2 'there was such shame on it, there was hug
Lack of options	<ul style="list-style-type: none"> no cure no medication no care planning opportunities 	#FGA1 'I mean I don't think that there is a cure,... an advantage, you know'. #FGA7 'is there medication?' #FGA6 'its hard to believe it the way it snowballs, probably still able to make for yourself'
2c Normative beliefs of the approval for help seeking for an early dementia diagnosis		
Family, friends, peers, colleagues, health professionals	<ul style="list-style-type: none"> family and peers of same age most likely to approve of help-seeking 	#FGC1 'I think that family would definitely be sup #FGA7 'well I think that em, you's (peers) would
2c Normative beliefs of the disapproval for help seeking for an early dementia diagnosis		
Elderly adults, young adults/teens, employers	<ul style="list-style-type: none"> young adults/teens least likely to approve elderly adults least likely to approve 	#FGC4 'like teenagers would probably laugh at ye #FGA# 'an older person, say a person in their seven
2d Control beliefs as supports for help seeking for an early dementia diagnosis		
Family, friends and peers	<ul style="list-style-type: none"> assisting with help-seeking/ identifying difficulties 	#FGB1 'this group (peers) is a very good group for
Health care system	<ul style="list-style-type: none"> GP's, and nurses specialist clinics health centres support groups 	#FGB3 'your local GP and your health centre, and y #FGB3 'the Alzheimer's society'
2d Control beliefs as difficulties/barriers to help-seeking for an early dementia diagnosis		
Fear	<ul style="list-style-type: none"> of diagnosis and its impact 	#FGC1 'well I think it's the fear' #FGC3 'fear, yeah'
Stigma of dementia	<ul style="list-style-type: none"> shame, secrecy reaction of others name calling/ status reduction 	#FGA4 'yeah I'd say there is a lot of secrecy invol #FGB1 'you would be afraid they would reject you #FGA4 'oh ah, she's gone doolally'
Lack of education/ awareness	<ul style="list-style-type: none"> not knowing the warning signs or symptoms not knowing where to go lack of media campaigns to inform lack of knowledge of preventative measures 	#FGC4 'I don't think that people understand in gene #FGC4 'I think it's like having nowhere to go...like #FGA1 'I think we need to talk about it more, an av #FGA2 'we need a campaign, that's what we need. #FGC4 'I just don't think they have enough informa
Accessibility of services	<ul style="list-style-type: none"> lack of screening opportunities difficulties within patient/GP communication rural location/ socially isolated personal and state costs 	#FGC2# 'you see doctors deal with different physic #FGC1 'I don't like this particular doctor and I did #FGC2 'on, eh, an Irish scale if the government dic
Coping style	<ul style="list-style-type: none"> avoidance denial humour 	#FGA4 'oh what do you want to do that for, sure are #FGB6 'like we had this bit of banter, and say, even

Table 3: Sociodemographic profile of the sample

Subscale		N=95	%
Age	50-54	30	32%
	55-59	23	24%
	60-64	19	20%
	65-69	23	24%
Sex:	Male	27	28%
	Female	68	72%
Education: Cert	Primary Cert	18	19%
	Secondary	38	40%
		30	32%
	Third Level	9	9%
	Other		
MMSE:	Score 26	3	3%
	27	7	7%
	28	10	11%
	29	16	17%
	30	59	62%

MMSE= Mini Mental State Exam.